

April 2024

Community Perspectives on Access, Quality, and Invasiveness of Dental Care

Table of Contents

Table of Contents2
Acknowledgments
Introduction 4
Methodology5
Key Themes6
Access to Dental Care6
<i>Key Theme: Dental coverage does not equal access</i> 6
<i>Key Theme: People understand their oral health is important – barriers to care are structural and systems-based</i> 8
Experiences with Dental Care9
<i>Key Theme: People's experiences with care are racialized and oral health outcomes are inequitable</i> 9
<i>Key Theme: Fear, trauma, and trust are intricately intertwined in impacting peoples' experiences with dental care</i> 10
Invasiveness of Dental Care12
<i>Key Theme: Invasiveness of dental care is fueled by the inaccessibility and unaffordability of care</i> 12
<i>Key Theme: "Invasiveness" is experienced within and outside of clinical settings and incorporates access, affordability, and patient choice</i> 13
Communities are eager to engage in designing and implementing solutions 14
Policy Recommendations16
Conclusion

Acknowledgments

This report and the associated community listening sessions were developed and conducted in collaboration with the specific guidance, support, and feedback of:

Adam Fox and Mannat Singh, Colorado Consumer Health Initiative
Milo Marquez, Colorado Latino Leadership, Advocacy, and Research Organization
Freedom Thompson and Sarah Maresh, Nebraska Appleseed
Ronald Browder and Lisa Stafford, Ohio Federation for Health Equity and Social Justice

While we do not name the community listening session participants here or throughout this report for confidentiality reasons, we are deeply indebted to their work, commitment and trust throughout this project.

This report was developed with support from the CareQuest Institute for Oral Health.

Introduction

Dental disease hurts more than our teeth, and <u>oral health is critical for overall health and</u> <u>well-being</u>. Dental disease is associated with a variety of acute and chronic health conditions, including heart disease, pneumonia, dementia, and diabetes. Good oral health can reduce the risk of pregnancy complications and support mental health. Despite these deep connections, the oral health care system in the United States is systemically separated from other areas of health care, including how care is covered, paid for, and where and by whom it is delivered.

Despite the importance of oral health, many people in the U.S. lack access to quality, affordable, and accessible dental care – about <u>one-third of adults do not have a yearly</u> <u>dental visit</u> and about a third of older adults have <u>lost at least six teeth due to dental</u> <u>disease</u>. Like other areas of health, structural racism shapes oral health policies and drives inequities in access to care and outcomes. Black, indigenous, and people of color, as well as individuals with low incomes and people with disabilities face greater barriers to accessing dental care and <u>more untreated dental disease</u> as a result. <u>Dental care also</u> <u>presents the highest financial burden of any health care service</u>, leaving care out of reach for millions of people and creating an impossible choice for many – <u>take on debt</u> to pay for care or suffer in pain.

Lack of access to care and inequities in outcomes are the result of policy choices, not personal responsibility. Research and advocacy consistently show that individuals <u>care</u> <u>about and understand the importance of their oral health</u> – it is considered a priority, and it is well understood that it is <u>connected to overall health</u>. However, the extent to which communities are engaged in conversations and decisions about the oral health policies that will impact their access and care varies widely.

To effectively move forward with any new policies or models of care, it is critical to prioritize the deep and meaningful engagement of communities to understand what people currently experience and what they want out of their care. To help better understand the perspectives of community members regarding access to and experiences with dental care, Community Catalyst held a series of "community listening sessions" with community members in three states. This report includes an overview of the methodology of these listening sessions, descriptions of key themes that arose, and recommendations for policy solutions to address the barriers community members named.

Methodology

In collaboration with community-based and advocacy organizations, Community Catalyst hosted listening sessions with community members in three states: Colorado, Nebraska and Ohio. In each state, we partnered with a local organization (see table below) with a strong track record of community engagement and experience working on oral health issues. Together, we hosted two community listening sessions in each state for a total of six sessions. Sessions were hosted virtually via Zoom. Community Catalyst staff facilitated the sessions and managed logistics, including notetaking and technical setup and support; the local partner organizations managed outreach and recruiting, follow-up with participants, and attended all sessions to support facilitation. Each local organization conducted recruitment in their communities; Community Catalyst did not limit the sessions based on identity group or any other standardized criteria, but rather relied on the community engagement expertise of the local organizations.

Each listening session lasted 90 minutes and was recorded with permission from all participants. Given participant schedules, the number of participants varied between the first and second sessions (see table below); however, each of the two sessions in each state included substantially the same invitee list. Community Catalyst staff met with the local partner organizations after the first session to debrief, address any participant or organization staff feedback, and adjust accordingly for the second session.

State	Local Partner Organization	Listening Session #1: Participant Count	Listening Session #2: Participant Count
Colorado	Colorado Consumer	12	6
	Health Initiative		
Nebraska	Nebraska Appleseed	15	13
Ohio	Ohio Federation for	8	6
	Health Equity and Social		
	Justice		

Community Catalyst staff collaborated with the local organizations to design conversation guides that included structured questions and prompts to guide the listening sessions. In the first session, participants were asked about their oral health, their experiences finding a provider and getting care, and their thoughts about the invasiveness of care and less invasive options. In the second session, participants were asked about if or how their oral health has impacted other parts of their life and their perspectives on addressing the barriers discussed in the first conversation, including what would make it easier to find a provider or get dental care, what would increase patient choice, and what would improve their experiences with care.

Session recordings and associated transcripts, along with facilitator notes, were used to identify the key themes described below.

Key Themes

The below section summarizes the key themes uncovered across the six listening sessions conducted. The themes centered around three overarching topics: access to care, experiences with care, and invasiveness of care. Overarchingly, the conversations point to a reality that having access to care is not a dichotomy where some people have it and others don't. Access to care exists on a spectrum that includes factors such as insurance coverage, the ability to find a dentist and get to the location where care is provided, and the ability to pay for services. Additionally, factors associated with quality of care, such as how patients are treated, experiences with discrimination, and invasiveness of care, intersect with issues related to access to paint a holistic picture of what it means for dental care to truly be accessible, affordable and respectful.

Access to Dental Care

Across all six listening sessions in the three states, similar access barriers arose related to insurance status, coverage of specific services, provider availability and accessibility, and social determinants, like transportation and language access.

Participants consistently described access as less of a binary – you have access or you don't – and more of a spectrum, naming multiple dimensions associated with access to care. Participants spoke about the ways that various aspects of access contribute to one another to determine how "accessible" the oral health system feels to them. Specific factors about the quality of and experiences with dental care are described in more detail below, but it is worth noting that participants consistently drew connections between access and quality – the quality of care received, and how individuals, their families, and their communities were treated when they accessed care, all contributed to how participants described experiencing access.

Key Theme: Dental coverage does not equal access

Participants consistently named that having dental insurance does not equal having access to care, which was particularly true for people with Medicaid coverage and especially so for adults covered by the program – participants noted that oral health care is noticeably more accessible for children than it is for adults. Participants also expressed frustration about feeling stuck in between making too much money to qualify for Medicaid or financial assistance and not making enough money to afford good care.

For participants who were covered by Medicaid, three main experiences arose that contributed to people not being able to get the care they needed:

- 1. It is very difficult and time-consuming to find a dentist who will accept
- **Medicaid.** Perhaps the most recurring theme related to access barriers across all the listening sessions was the lack of dentists who accept Medicaid. Participants described needing to call many clinics or offices to be able to find a dentist who would accept Medicaid and was taking new patients. As a result, participants also described having to travel long distances or wait a long time for appointments with the few available providers. Participants also noted that this barrier is only exacerbated by a lack of access to reliable transportation. Lack of dentist participation in Medicaid combined with the additional <u>burden placed on</u> communities with low incomes to get to those dentists has been documented, but persists nonetheless. This leads to additional time and financial costs for people who have to wait for long periods of time to be seen, for those who have to take time away from work, and for those who may need to pay additional money for transportation services. Finally, many participants described the oral health impacts of not being able to find or get to a provider for routine care.
- 2. **Medicaid does not always cover needed services.** Even for participants who were able to find a dentist who accepted Medicaid, many described unmet needs, especially for restorative services like root canals, as a result of these services not being included in their Medicaid coverage. Participants expressed frustration and confusion about why services weren't covered even when their provider said they needed them. For example, a participant from Nebraska shared, *"Medicaid won't cover my baby's braces. They said it wasn't medically necessary even though the dentist is the one who said it is medically necessary."*
- 3. Finding a dentist and having your care covered does not equate to a more positive or less invasive experience. Many participants described being treated poorly by providers or clinic/office staff and attributed this treatment to their Medicaid coverage. Black and Latino communities, communities with low incomes, immigrant communities, people who speak a language other than English, and people with disabilities were all mentioned as facing specific barriers and receiving poor treatment. While aspects related to quality of care and treatment are described in more detail below, participants specifically named this pattern in connection to access and Medicaid status. One participant from Nebraska described being treated overly harshly by dental providers and experiencing them as having less compassion for their pain. They said, *"I feel that some of that is probably rooted in racism and classism because I have Medicaid."*

Key Theme: People understand their oral health is important – barriers to care are structural and systems-based

66 People never stop to think that it is a luxury to take care of your oral health.

Nebraska participant

Discussions about access to care consistently led participants across all three states to identify common structural barriers. Across all the listening sessions, when participants were asked for their general thoughts on oral health, conversations quickly turned to systemic barriers (and facilitators) to access. Across different insurance statuses, one of the most common systemic factors participants discussed was cost. Participants described the cost of dental insurance premiums, deductibles, and co-pays, as well as costs associated with needed services that were not covered. Even when there were no direct costs for appointments or services, participants described costs associated with transportation, child care, and taking time off work to access appointments. Especially for lower-income participants and those with a lot of other competing financial needs, the cost of dental care was just too high for many people to access. For example, one participant from Ohio stated, *"People who are not poor don't understand that when your priority every day is putting food on the table and finding a place to live, other issues that are not pressing you at the moment, sometimes get pushed to a back burner."*

The above quote displays not only the prohibitive costs of accessing dental care, but also another key theme from the listening sessions: the reality that <u>communities care about</u> and <u>understand how important their oral health is</u>. While narratives suggesting that oral health issues are the result of a lack of understanding or care about oral health and that dental care is about "personal responsibility" often continue to inform oral health policy and practice, these listening sessions confirmed that people value and understand the importance of receiving dental care and maintaining their oral health. **The barriers to good oral health are structural and systems-based, not individual.**

"Families want their kids and their family members to have all the best health [care] they can. There's no means test on loving your children. It's not a matter of desire or a matter of priorities, it's just a matter of severity of poverty." -Ohio participant

Not only did participants continually name oral health as a priority for them, but many naturally named connections between oral health and other areas of health and life. For example, participants named the role dental problems have in interrupting children's

ability to learn in school as well as the connection between oral health and Alzheimer's and heart disease. For example, one Colorado participant described their grandmother's experience: *"This correlation between the teeth and the heart – my grandma, she died. She was already on a blood thinner and they had taken some of her teeth out that day and so she bled. My grandma should have still been living."*

As noted above, participants described particular difficulty finding a provider who accepts Medicaid; however, even participants with private and other forms of insurance described similar barriers: lists provided by insurance companies may be out of date; providers who accept a patient's insurance may not be accepting new patients; and appointment wait times may be unacceptably long, especially when someone is looking for an appointment to address an acute oral health issue. Additionally, participants described further time constraints associated with taking time off work – especially if it is not paid – and travel time to appointments.

Finally, all the above barriers are intensified for people who have other needs to consider. Several participants described having a disability and/or speaking a language other than English as presenting specific systemic barriers or intensifying existing ones. For example, finding a provider who accepts Medicaid, who is trained to work with people with intellectual or developmental disabilities, who speaks a language other than English, or who has a clinic or office space that is physically accessible is already difficult; if a patient needs a provider who meets more than one of these criteria, the pool of providers narrows even further.

Experiences with Dental Care

As noted above, being able to find a provider, get an appointment, and pay for care was only part of the picture of access for participants. Many participants described the quality of the care they were able to get as a component of access. For example, someone may have insurance, be covered for the services they need, and be able to get an appointment with a provider. However, if they show up to the appointment and are treated poorly by the front desk staff or are not given a choice in the specific services they can receive, this can impact peoples' feelings about their access; they might be physically able to get care, but if that care isn't respectful and transparent, it doesn't fit the bill.

Key Theme: People's experiences with care are racialized and oral health outcomes are inequitable

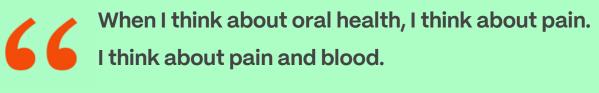
The understanding that barriers to care are systemic led naturally into conversations about inequities in access to care and oral health outcomes. Participants consistently named that Black and Latino communities, communities with low incomes, immigrant communities, people who speak a language other than English, and people with disabilities face specific barriers and poor treatment when accessing oral health care. One participant from Nebraska described this inequitable treatment and its structural roots: *"It's no accident that the poor and heavily minority communities oftentimes cannot find compassionate dental care."*

Many participants named that they felt their experiences with dental care were based on their Medicaid status. Participants described feeling like they were treated worse by both providers and front-of-office staff once they disclosed that they were covered by Medicaid and that the clinical advice they receive is based on the fact that they have Medicaid, not necessarily on what is best for their oral health. As one participant from Ohio described, *"Looking the way that I do, as a white female that doesn't seem like she would present a Medicaid card for her health care, it was like a needle on a record. I could see the difference between the way I was treated and the way some other patients of color [were treated]." This same participant also shared that she had previously been privately insured and noticed a distinct difference in how she was treated when she had private insurance versus Medicaid. Similarly, a participant from Nebraska described, <i>"I don't always feel as a patient, especially a patient that has Medicaid, is shown very much respect ... it felt like they felt entitled to be rude because we were Medicaid patients."*

Key Theme: Fear, trauma, and trust are intricately intertwined in impacting peoples' experiences with dental care

Across the sessions in all three states, participants routinely discussed dental fear and trauma as well as the trustworthiness (or lack thereof) of dental providers and the oral health care system as a whole. Participants specifically named pain, the invasiveness of care, and access barriers as consistent sources of dental fear and trauma. Participants also described the nuanced ways that these components intersect with each other to inform broad experiences with dental care. In many of the conversations described above about discrimination or poor treatment in dental settings, participants discussed how being treated poorly, in and of itself, can be traumatic.

Participants repeatedly described their experiences with dental care as being marked by pain. One participant from Nebraska put it succinctly:



Nebraska participant

Participants described both the trauma associated with the chronic pain that comes with having untreated oral health problems – without good access to regular dental care, many

participants described having to live with ongoing dental pain – and the acute pain of undergoing invasive dental procedures. Relatedly, many participants also described invasive care, especially care marked by drills, needles, and surgeries, as being at the root of a lot of dental fear. Participants also described the often arduous and time-intensive process of trying to access good quality care as traumatic and went on to talk about the cycle of access problems and chronic pain: lack of access to good quality dental care can lead to chronic dental pain and trauma; pain and trauma can lead to a lack of trust in the dental system that limits peoples' ability to access care. Additionally, lack of access to care, or long wait times for acute needs, can lead oral health problems to worsen and require more invasive care once a person can access a provider – this can exacerbate the cycle of lack of access, pain, and lack of trust.

Participants named the importance of early experiences with dental care and the longterm impact it can have on their perceptions and experiences with the oral health system. In particular, participants described how even one bad experience can create trauma, lead to ongoing fear, and make it hard to trust providers in the future. One critical aspect of the conversations about experiences with dental care was the emphasis participants placed on generational experiences and trauma. Several participants described wanting their children to have better dental experiences than they did, like the participant from Nebraska who stated, "As a mom, I'll always put my kids first with their medical or dental care. I'll deal with toothaches and physical pain." Many participants also described watching their parents and/or grandparents have invasive or otherwise traumatic experiences with care that instilled fear in them from a very young age. Participants also described generations of pain and trauma associated with not being able to access care at all or with only having access to care that was disrespectful or discriminatory. As one parent from Nebraska described, "His [child's] oral health is really downhill because of that gap in coverage and access, and because of the stuff they did to him in the past. For a while, he wouldn't even brush his teeth because he was so terrified of the pain. And my younger kids watched how he reacted, so they didn't want their teeth brushed. We had to pin them down and force them to brush their teeth which isn't good either. It's a neverending cycle."

Conversely, participants described how early experiences with care that are respectful can set the stage for good long-term relationships with the dental system and with one's oral health. Participants described specific facilitators of good experiences with dental care, including: having access to patient advocates or care coordinators who can help explain care, follow up about appointments, and provide language interpretation services; having a provider they trust and feel comfortable with; and being able to see the same provider consistently, which can help build a good working relationship. As one participant from Colorado shared, *"I want somebody who cares, who's competent, who has a heart, compassion, and has some kind of willingness to humble themselves."*

Invasiveness of Dental Care

Whether in the context of pain and trauma or not, participants routinely described experiencing their dental care as invasive. Typically, conversations about invasiveness, and minimally-invasive care (MIC) in particular, focus on clinical experiences and specific dental procedures that are less physically invasive. The increase in availability of <u>MIC</u> <u>services can have an important impact on patient experience</u>; however, these listening sessions revealed that, in order to fully understand how people conceptualize the "invasiveness" of dental care, we need to also focus on accessibility, affordability, and patient experience.

Key Theme: Invasiveness of dental care is fueled by the inaccessibility and unaffordability of care

Across all the listening sessions, the inaccessibility and unaffordability of dental care, as well as the way those barriers resulted in more severe dental disease and more invasive treatment, was very central to the discussions. Many participants named that out-of-pocket costs are too high and that there is a lack of transparency in the cost of dental services. Discussions around cost and affordability mirrored research showing that <u>dental</u> care presents the highest financial burdens of any health care service and that it is a big contributor to medical debt. Participants frequently spoke about how the lack of affordability of dental care contributed to it being inaccessible. Many participants discussed being forced to choose between paying for care and paying for other priorities such as food, housing, or utility bills and spoke about how these choices are untenable. Because participants valued their oral health, but were often unable to afford or access the care they needed, these choices felt invasive. Under these circumstances, it is understandable that most people prioritized more urgent needs. However, participants underscored that these choices were a result of a lack of resources, not a lack of understanding or care about oral health.

Participants were also very clear in how they saw the high cost of care contributing to (often unnecessary) invasiveness. As one participant from Colorado stated, *"People have never been able to afford a dentist, so they let things go until there's a horrible toothache, they end up needing a root canal ... I just wish that there were places in our community that would be visible, accessible."* While most participants were not familiar with the framework of MIC or specific MIC procedures, it was common for the concept of invasiveness to come up when participants spoke about the consequences of inaccessible dental care – many spoke to similar situations described by the participant from Colorado where they could not afford or otherwise access dental care and ended up needed more invasive care as a result.

Key Theme: "Invasiveness" is experienced within and outside of clinical settings and incorporates access, affordability, and patient choice

One of the most consistent themes heard across all listening sessions was that the invasiveness of the dental care system has produced lifetimes of fear, trauma, pain, and distrust. This included people's experiences trying to access and afford care as well as experiences receiving care itself. Participants described the trauma as a result of chronic pain due to avoiding care and the trauma from the care they received; they also described how these two sources of trauma are mutually reinforcing and feel "inhumane." Participants across several sessions also reported feeling like sometimes teeth are pulled unnecessarily and not knowing if that is because it is the only option or because it is more cost-effective for the dentist to perform more invasive services.

Though most participants were unfamiliar with the specific framework of MIC, when MIC was described, participants were of two minds – on the one hand, many said they would be interested in receiving less invasive services, especially if it meant less pain and fewer traumatic experiences. For example, one participant from Nebraska stated, *"My baby just had a cavity filled and if there's a less invasive way to do that that's less painful, that should be available to everybody regardless of your insurance status."*

It makes no sense to say pain comes with poverty.

Nebraska participant

"

On the other hand, many participants described a history, especially among Black communities, of being "experimented on" with new procedures that were not well tested or proven to be safe. In several instances, participants held both perspectives at the same time.

Overall, these conversations revealed the need to simultaneously ensure a wide range of dental services are available to all people in their communities, regardless of their insurance status, while also taking seriously the reasons why some people might not want MIC, because of both historical and contemporary experiences with trauma at the hands of the health care system. Overall, these discussions revealed that people can experience racism, classism, or otherwise be treated disrespectfully regardless of the invasiveness of specific services.

While the inaccessibility and unaffordability of care can exacerbate oral health problems and increase the invasiveness of the treatment needed, the conversations made clear that there is much more than the specific clinical service being provided that shapes the degree of invasiveness someone experiences. As described above, watching family or community members suffer pain from invasive care or an inability to access care at all contributed to participants feeling like dental care was invasive. Additionally, participants described experiencing discrimination or poor treatment in dental settings and recognizing the way that structural racism informs access to and affordability of care for themselves and their communities. While these experiences have little to do with traditional and clinical frameworks of MIC, they contributed to experiences of invasiveness that participants described.

In particular, participants described how infrequently they were provided with real choices – in terms of the type and invasiveness of the dental procedures they received, but also in terms of where they could go to access care and their ability to choose a provider. The latter was especially true for people with Medicaid, who often needed to travel long distances to find even a single provider who would accept their insurance and could provide an appointment. A few participants described instances of feeling like they *were* able to make informed choices about their care when they had a provider they trusted. One participant from Colorado shared, *"It's not that difficult if you trust your health care provider to have the discussions."* Another participant from Colorado explained an instance in which they chose a treatment option that was different than what their provider initially suggested: *"It was my choice. It didn't mean I stopped trusting my doctor, I actually confided in her and thought 'Well she can't know everything about every single thing that's out there...each individual is different."*

The lack of choice patients experience can establish a foundation of discomfort, distrust, and disrespect with the experience of care that participants described as feeling invasive, regardless of the types of services they were offered. For many people, the "choice" becomes painful, costly, and invasive experiences or avoiding care altogether.

Communities are eager to engage in designing and implementing solutions

Despite incorrect narratives of "personal responsibility", barriers to access and affordability, and experiences of discrimination and trauma, people in communities know what they want out of their oral health care and are eager to participate in designing new solutions. As described above, participants discussed components of positive experiences with care or treatment, and many expressed an interest in having a respectful relationship with a consistent provider. When responding to questions about how the dental care system could be improved, participants consistently expressed a desire for involvement and collaboration, both in their care and in policy solutions to improve the oral health system. As one participant from Nebraska expressed:

"Sometimes I feel like the judgments that they [providers] make, which may be 'Oh I'm going to pull that tooth,' they're making those decisions for that person. There's a lot of

great dentistry ... but they open up these clinics and we don't know if we should trust them, if they're just experimenting on us and prejudging us and just going to rip out our teeth or if they're going to help us and walk us through this. Is this going to be an intimate experience? Because these are our daily tools of living and eating, so it should be a lot more intimate. These are not intimate experiences with our dentists, we see them every once in a while and we need more intimate care."

Many participants also expressed support and care as others spoke about their experiences and a desire to be involved in positive systems change. In one conversation with participants in Nebraska, a participant spoke positively about their personal experiences with care, which was paired with shock and surprise at many of the stories being told and a desire to improve the oral health system for everyone: *"I've never had any of these negative experiences, even being poor. I'm shocked, I want to do something to create change, I'm angry."*

In fact, across all the listening sessions, participants demonstrated a strong tendency towards action and naturally moved the conversation into ideas and strategies for change. For example, one participant from Colorado expressed, *"Can we start implementing some policy based upon all this Latino/gente wisdom, knowledge, cultura? Because we have it all from the field to the tower, but it's all fragmented and separated."*

In several instances, participants reported that, after the first session, they independently did research and had conversations with others to better understand the problem and opportunities for change. For example, one participant followed up with the partner organization to share that they did some additional research on racial disparities and were spurred to action from what they heard people report on during the first conversation. In another situation, a person who works in a dental clinic shared themes with their employer to pursue practice changes in real time.

When communities were asked directly to share their ideas around opportunities for change, they responded with a range of solutions that were connected to insurance coverage, dental workforce, and community outreach. Below is a (non-exhaustive) list of some of the priorities that arose from these conversations:

- Increase the number of dentists who accept Medicaid
- Expand the pool of providers in general, but specifically, those who serve lowincome communities, people with substance use disorders or in recovery, people with intellectual and developmental disabilities, and people who speak a language other than English
- Provide transportation, case management, and other coordination resources for patients to offset the financial and logistical barriers to accessing care

- Create pipeline programs to have a dental workforce that is representative of the communities it serves
- Implement models of care that have providers out in the community, which will help them be more informed about the context in which their patients live
- Create opportunities for oral health education that are less focused on convincing people that oral health is important they know that already. Focus on giving people the information they need to access the resources available to them, while also making more resources and care available
- Create centralized and trusted spaces for community members to share information and resources with each other, especially about where to find a provider they can trust

In general, participants were very motivated to be involved in change at all levels. As one participant from Colorado remarked, *"I don't think this is just by coincidence. If you really want to help people, your policy's going to reflect that. If you really don't, it's also going to reflect that. On a greater level, this is policy level stuff. It's a grassroots cause, but it's not going to make an impact on a larger scale unless we ... take it to policy. And it happens by hearing these stories."*

Policy Recommendations

At a high level, these conversations highlighted the critical need to center community perspectives in the design and implementation of equitable solutions. Communities are already engaged in efforts to share their experiences with each other and develop solutions that will address their needs and desires for accessible, affordable, high-quality oral health care – this engagement and expertise must be centered in policy and practice solutions. Advocates should take advantage of community interest in problem-solving and work to build power with marginalized communities rather than only seeking to engage communities in the work and strategies they have already designed.

Based on the discussions with participants across the three states, several policy opportunities arose that would address the barriers and ideas for solutions that participants named.

Make Medicaid adult dental benefits mandatory

Currently, state Medicaid programs are not required to cover any dental care for adults. Most states provide some coverage, but the optional nature of these benefits means they are inconsistent and continuously at risk of being cut. Cost barriers to care are exacerbated by the optional nature of Medicaid adult dental benefits because <u>states have</u> wide discretion in which services they do and don't cover, with many leaving out key restorative services. Many states also have financial "caps" that limit the dollar amount of services that will be covered, leaving patients with the impossible choice of going into debt or foregoing needed care.

While many states have made progress on their Medicaid adult dental benefits, requiring all states to cover a <u>standardized and comprehensive set of dental benefits</u> for adults would reduce confusion and state variability, improve access to care for communities with low incomes, and reduce the financial burden associated with accessing critical oral health care. Ensuring that commonly needed services are consistently covered could also incentivize more dental providers to accept Medicaid; the financial risk to providers would decrease without the uncertainty associated with potential benefit cuts. Given the extent to which participants expressed barriers related to covered services and costs in Medicaid, ensuring comprehensive and standardized coverage should be a priority, especially for communities with low incomes.

Improve scope of practice and expand the dental workforce

Throughout the listening sessions, participants repeatedly discussed how difficult it was and how much time it took to find a dental provider, especially one who accepted Medicaid, spoke a language other than English, and/or was accessible to people with disabilities. This is reinforced by data showing that <u>nearly 80 million people in the United States live in areas without enough dental providers</u>. Several opportunities exist to improve the oral health workforce and address these barriers, including:

- *Expanding the scope of dental hygienists:* Dental hygienists provide important preventive services and can provide a lot of routine care that helps maintain oral health. State law varies on whether hygienists can practice independently, work in community settings, or provide specific MIC services. Expanding dental hygienists' scope of practice to include <u>MIC services they are trained to provide</u> and to work in community settings, either independently or as part of a team, can increase the availability of providers and make dental care more accessible.
- Authorizing dental therapy: Dental therapists are licensed dental providers who work under the supervision of a dentist to provide routine preventive and restorative care. Thirteen states have authorized dental therapists to practice and they have shown to improve access to care, especially in community settings, and build a more culturally representative workforce. Passing legislation to authorize dental therapy in additional states can address barriers raised by participants about trouble finding a provider and the lack of providers who are racially or culturally representative of the communities they serve. Because they often work in their own communities, dental therapists can establish a high level of trust with their patients, which was another key theme participants discussed in the sessions.
- *Training and reimbursing community health workers:* Community health workers (CHWs) bring culturally grounded health education and resources into communities and build trust with patients. Providing training and certification for

CHWs in oral health and ensuring they can be reimbursed for their services can help address barriers raised by participants about the lack of locally available providers, information, and resources.

Regardless of the specific policy, oral health workforce solutions should be targeted at increasing the number of dental providers who accept Medicaid, who are racially and culturally representative of the communities they serve, who are based in community settings, and who are poised to develop long-term, trusting, and respectful relationships with community members. All of these were key concerns among the listening session participants, who, like the majority of people, understood the importance of dental care and valued their oral health, but identified structural barriers and the need for systemic solutions to make the oral health system more accessible and equitable.

Expand access to minimally-invasive care and patient choice

One outcome of dental access issues, including coverage barriers and inability to find a provider, is worsening oral health problems and the resultant need for more invasive care. Participants consistently described the invasiveness of their dental care, either because they were not given a choice of less invasive services or because lack of access and/or trauma resulted in not seeing a provider until oral health issues had progressed to the point that invasive or surgical options were the only ones available. Several participants specifically named the relationship between invasiveness and racism, stating they were often unsure if recommendations for invasive care were out of clinical necessity or a result of their race and/or Medicaid coverage status. Research does show that Black patients, in particular, are more likely to receive recommendations for invasive treatment rather than services that could allow them to keep their teeth and prevent tooth decay in the future. Participants expressed both interest in and hesitancy about newer treatment options, like MIC, particularly in the context of how racism shows up in dentistry. These conversations made clear the need to improve access to dental services across the board, including MIC services, and to keep patient choice at the center of treatment options.

Policy opportunities to address clinic invasiveness include:

- Authorizing a range of dental and medical providers to administer the MIC services that they are trained to provide. This includes ensuring dentists, dental hygienists, dental therapists, primary care providers (including nurse practitioners and physician assistants), and community health workers all have relevant MIC services included in their scope of practice and that public and private insurance systems reimburse for those services.
- Ensuring insurance, including Medicaid, Medicare, and private coverage, cover the full range of needed services, including <u>silver diamine fluoride application and</u> <u>other forms of MIC</u>. Ultimately, the full range of care – from minimally invasive to invasive restorative procedures – should be available to people when they need it,

and decisions about what type of care is right should be made in collaboration between patient and provider. Sometimes, more invasive services will be preferable, whether because it is the only option (e.g., a broken tooth that needs to be pulled or restored) or because it is what a person prefers (i.e., less invasive approaches weren't effective in the past and/or it will save time and be more convenient to get a single, more invasive procedure). Patient choice should be at the forefront of conversations about MIC policy to ensure care is trauma-informed and trustworthy.

Participants also described experiencing discrimination or otherwise being treated disrespectfully, and generational trauma associated with dental care as marking their experiences with the oral health system as "invasive." This mirrors research showing that about half of Black, Hispanic, and Asian adults have experienced discrimination in dental settings. Throughout the listening sessions it became clear that, even if someone has access to and chooses MIC services, they can still experience racism, discrimination, or trauma in ways that make this care feel invasive. Ultimately, good policy that ensures the wide range of needed dental services, MIC and otherwise, are available to people regardless of insurance status and in community-based settings is necessary, but not sufficient. Training, education, and practice-based improvements are also necessary for ensuring care is trauma-informed, respectful, and culturally appropriate.

Address social determinants of oral health

Across all of the listening sessions, participants spoke to various social determinants that impacted their ability to access and afford dental care. In particular, barriers arose related to time off work, child care needs, and transportation, especially for people with Medicaid who had a lot of difficulty finding local providers who would take their insurance. Many of the policy priorities listed above are necessary for ensuring universal and comprehensive coverage of oral health services, which can support affording the direct costs of accessing dental care. However, these conversations made clear that there are a variety of considerations that contribute to the holistic cost of a dental visit, even outside of the cost of services or copays. These issues also need to be addressed via policy solutions to ensure oral health care is practically affordable, not just covered.

Policy solutions include:

- *Covering non-emergency medical transportation (NEMT):* NEMT is a covered Medicaid service in all states. Like adult dental care, NEMT is an optional Medicaid service, but is critical for supporting low-income and people with disabilities to access dental (and medical) appointments.
- *Care coordination and patient navigations:* Participants discussed the importance of non-clinical support for getting and keeping appointments and understanding key information about their coverage and care. Many participants named challenges associated with competing needs and priorities and confusion arising

from different providers offering different information. While managed care arrangements exist in many state Medicaid programs, they are often not maximized to ensure full care coordination and patient engagement. Patient navigation can further support addressing barriers to access, but it is not routinely covered by Medicaid or private insurance.

 Medicaid Health Related Social Needs (HRSN) Waivers: States can use Medicaid 1115 waivers to implement innovative projects to better improve coverage for people with low incomes. This mechanism can be used to allow <u>Medicaid to cover</u> food, housing, or other health-related services that would not usually be covered by health insurance.

Conclusion

The community listening sessions described here reflected several important key themes about community perspectives on access to and experiences with dental care. Across three states, people were clear that they understood the importance of oral health, its connection to other areas of their health and lives, and the structural and systems-based barriers that have often left dental care out of their reach. People clearly described key access barriers: lack of coverage of needed services; lack of provider availability and accessibility; racism, classism, and other forms of discrimination; and the resultant fear, trauma, and untrustworthiness of the dental care system. They also were eager to recommend clear solutions for policy and systems change that can be addressed via coverage requirements, dental workforce expansions, minimally-invasive care, and opportunities to address social determinants of health.

Overall, the lack of trustworthiness of the oral health system was frequently described as something that lives palpably in peoples' family histories – the pain and trauma participants described with the oral health system did not start or end with them. It is clear that patient choice and community-informed solutions must be at the forefront of all oral health policy decisions to ensure care is trauma-informed and trustworthy.